

NATIONAL CANCER INSTITUTE

**Strategic Plan to Reduce and
Ultimately Eliminate Health Disparities**

Prepared for the

**NATIONAL CENTER ON MINORITY HEALTH AND
HEALTH DISPARITIES**

NATIONAL CANCER INSTITUTE
NIH Comprehensive Strategic Plan
To Reduce and Ultimately Eliminate Health Disparities

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Strategic Plan to Reduce and Ultimately Eliminate Health Disparities

NCI MISSION/VISION STATEMENT

The National Cancer Institute's (NCI) mission is to stimulate and support scientific discovery and its application to achieve a future when all cancers are uncommon and easily treated. The fact that the burden of cancer is borne unequally in our society is not only a challenge to science but a moral and ethical dilemma for our Nation. The overarching goal of the NCI articulated in this Strategic Plan is to understand the causes of cancer health disparities and develop effective interventions to reduce and, ultimately, eliminate them. To accomplish this goal, NCI will invest in research to examine the inequalities in cancer and the social, cultural, environmental, biological, and behavioral determinants of cancer, the interactions among them, and the mechanisms by which they contribute to disparities in cancer care and prevention. Further, NCI will support initiatives to develop sustainable interventions, and identify priority areas for future policy development that are based on scientific and expert evidence to ameliorate cancer health disparities.

OVERVIEW OF NCI STRATEGY FOR ADDRESSING HEALTH DISPARITIES

The Overall Challenge

Despite progress in biomedical science over the past several decades that has increased longevity and improved quality of life for many in our Nation, a heavier burden of disease continues to be borne by some populations, particularly minorities, the poor and underserved. For example, the death rate from prostate cancer among African American men is almost twice that of white men, and stomach cancer mortality is substantially higher among Asian-Pacific Islanders, including Native Hawaiians, than other populations. Cervical cancer incidence in Hispanic women has been consistently higher at all ages than for other women, and African American women have the highest death rate from cervical cancer. Overall, men are about 50 percent more likely than women to die from cancer, and among all women, Alaskan Natives are about 30 percent more likely to die from cancer. It is these disturbing statistics coupled with the fact that reductions in cancer incidence and mortality are occurring in many, but not all, sectors of our Nation, that prompts NCI to examine major determinants of cancer health disparities (e.g., poverty, culture, and social injustice). It is the interrelationship among these factors that must be carefully weaved into the cancer research agenda in order to remedy the unequal burden of cancer.

The National Cancer Institute is strongly committed to a research program that will address these cancer health disparities across the cancer control continuum from prevention to end of life care, consistent with recommendations in the Institute of Medicine's 1999 report, *The Unequal Burden of Cancer*, the Institute of Medicine's 2002 report, *Unequal Treatment*, and reflected in the Healthy People 2010 goal to eliminate racial and ethnic health disparities. Beginning with the

FY 2002 Bypass Budget document (published in October 2000), “Reducing Cancer-related Health Disparities” has been highlighted as a major priority “challenge” for the Institute. Substantial planning has gone into formulating this document, *The Nation’s Investment in Cancer Research*. Mandated under the National Cancer Act of 1971 (P.L.92-218), this document is designed to provide the President each year with a description of scientific opportunities in cancer research as he formulates his budget request to Congress.

To direct the implementation and coordination of these activities, support NCI health disparities research opportunities, and to provide an organizational locus for NCI in translating discovery into delivery, NCI established the Center to Reduce Cancer Health Disparities (CRCHD). NCI intends to expand the capacity of the NCI Center to Reduce Cancer Health Disparities (CRCHD) to accomplish these goals.

Through NCI-supported research and extramural programs, CRCHD’s activities are designed to develop a better understanding of the causes of disparities and provide scientifically-based evidence to support the development of effective strategies to intervene where disparities exist. NCI also has established a variety of infrastructures and initiatives to improve understanding of disparities and develop strategies and interventions to overcome them. These activities provide a firm foundation from which to expand and intensify our efforts as the Institute moves forward to “bridging the gap” between research discovery and service delivery.

Major Strategies For Addressing Cancer Health Disparities

The objectives of the NCI aimed at reducing and ultimately eliminating cancer-related health disparities will continue to strengthen and expand many ongoing activities, and establish new initiatives. Some initiatives may overlap or interface with more than one of the categories listed below. For example, an initiative may provide infrastructure for conducting clinical trials aimed at developing new or improved approaches to research in treating cancer. Moreover, improving participation in these trials by ethnic and racial minorities may require communication/outreach activities and additional research to understand how best to engage in effective communication, education and outreach. Recognizing that such overlaps may exist, this Plan outlines objectives within the following categories: expanding research, building research capacity and infrastructure, and expanding community outreach and information dissemination to impact on the elimination of cancer health disparities.

RESEARCH:

Disease always occurs within a context of human circumstances. In combination, risks related to genes, individual behaviors, social and environmental circumstances contribute to disease susceptibility. Moreover, social position, economic status, culture, and environment are among the more critical determinants of who is born healthy, who grows up healthy, who sustains health throughout his or her life span, who survives disease, and who maintains a good quality of life after diagnosis and treatment. NCI’s long-term investment in biological research and our more

recent investments in behavioral research have helped us make enormous strides in understanding how biological and behavioral factors determine risks for developing or dying from cancer and how interventions can modify these risks. Much less is known, however, about the effect that factors such as social position, economic status, cultural beliefs and practices, and environmental exposures have on cancer risk. If we are to reduce these disparities, the relative importance of social causes to their development and their relation to factors that result in unequal access to high quality cancer diagnosis and treatment must be explained. To do this, we must increase fundamental research into the social causes of health disparities, the psychosocial factors that mediate them, and the biologic pathways that can explain their impact.

NCI has developed and will pursue a research framework that builds upon the growing evidence that socioeconomic, cultural, health care provider, institutional, and environmental factors contribute substantially to cancer-related health disparities. The elements that influence health disparities are complex, and their interactions are largely unknown. While health disparities have been framed historically in the context of racial and ethnic disease differences, racial and ethnic classifications have always been socially and politically determined and have no legitimate place in biological science. There is broad agreement among experts that racism, borne of racial and ethnic classifications, is rooted in the erroneous concept of biological superiority and is a part of the cultural framework of societal, institutional, and civilizational values that continues to shape scientific thought. CRCHD has launched a series of workshops and seminars through which we can better address, using new frameworks, the fundamental aspects of population diversity and the development of diseases. The recommendations emerging from these meetings will form the foundation for NCI's research and program development. The power of scientific discovery must be used to elucidate the meaning and effect of the human circumstances in which differential disease burdens occur.

In our national effort against cancer, there is a critical disconnect between scientific discovery and cancer care delivery, and this disconnect is itself a key determinant of the unequal burden of cancer in our society. Barriers that prevent the benefits of research from reaching all populations, particularly those who bear the greatest disease burden, must be identified and removed. To achieve this objective, CRCHD is designing a "patient navigator" concept patterned after similar programs pioneered at Harlem Hospital over 10 years ago. This program would assist patients with abnormal findings or a diagnosis of cancer in navigating and, when needed, circumnavigating the hospital and human services bureaucracies to accomplish the necessary follow-up and diagnosis of abnormal findings on cancer screening to treatment. Further, NCI will develop new intergovernmental and public/private partnerships to improve the dissemination and diffusion of evidence-based interventions and encourage the development of health care policies for underserved communities.

In summary, to reduce cancer-related health disparities in our society, we must understand where biological, behavioral, social, economic, cultural, and environmental factors interface. We must separate myth from reality to determine what does and does not contribute to these disparities and use that insight to develop new interventions. And we must design new research investments

to explain:

- The relative importance of social, cultural, and environmental determinants of cancer
- How social, cultural, and environmental factors interact with biological and behavioral determinants
- By what mechanisms social, cultural, and environmental determinants may increase cancer incidence and mortality and contribute to cancer-related health disparities

The Need to Measure and Monitor Cancer Health Disparities

Two key questions emerge:

1. To what extent can prevention, early detection, treatment, and communication interventions effectively reduce cancer-related health disparities?
2. How can we best measure and monitor cancer-related health disparities across the spectrum of cancer incidence, stage of disease at diagnosis, disease recurrence, quality of life, and cancer mortality?

Over the past few decades, NCI has worked with other agencies to create a national cancer surveillance system for tracking cancer trends. At the heart of this system is the monitoring of cancer incidence— the number of people per 100,000 who develop cancer in a given year - and cancer mortality— the number of people per 100,000 who die from cancer each year. The system is also able to track cancers that may be declining or on the rise. Because of cancer surveillance, for example, we know that since 1990, the rates of both new cancers and deaths have fallen for all cancers combined and for most of the top 10 cancers, reversing a decades-long trend of rising rates in the United States. However, we are striving to build a surveillance system that not only tracks cancer statistics, but also helps us form hypotheses for cancer research, make critical scientific and public health decisions about this disease, develop prevention and control measures, and assess whether interventions are making a difference. Recent rapid advances in computerized information technology, increasing diversity in the U.S. population, and changes in health care delivery present new challenges to building such a surveillance system. For NCI to continue its pivotal role in effective and comprehensive national surveillance in a changing cultural, social, and technological milieu, we must respond on at least three fronts.

First, we must improve surveillance activities on several levels. We must create up-to-date statistical and analytical measures and improve the ways we apply the data. NCI's Surveillance, Epidemiology, and End Results (SEER) program must cover a broader spectrum of the population and compare information on why people get cancer and how it is treated with outcomes such as quality of life, and mortality. We must improve the measures we use to track cancer risk, screening practices, treatment, quality of life, quality of care, and morbidity. Improved surveillance programs must also integrate measures related to physicians, health systems, cancer communities, and policy into local and regional databases. We need to apply

these comprehensive improvements to help the cancer community identify areas to target for research and for health policy and planning.

Second, we must develop research tools that will allow us to track cancer trends more completely and more precisely. We must improve the way we make cancer surveillance data available electronically to ensure the privacy and confidentiality of individuals. New trend modeling techniques are needed to help us explain the trends across the cancer continuum. Health-related geographic information systems are needed to examine regional cancer data on individuals in relation to potential environmental exposures. Cancer maps must be refined to allow easier application of statistical analyses that measure cancer patterns and identify cancer clusters.

And third, we must enhance dissemination of surveillance data to scientists, the public, and policy makers. Cancer surveillance data will have its greatest impact on reducing the cancer burden only if it is provided in a timely manner and in a readily usable format to those who need it.

RESEARCH CAPACITY AND INFRASTRUCTURE:

Training and career development for the next generation of scientists remains one of our most important challenges. The scientists of the future will need to be more versatile in their use of new technologies, able to work in teams to understand the complicated environmental, lifestyle, genetic, and molecular variables contributing to human cancers, and better prepared to translate discoveries into public benefit. We need to implement and sustain multiple long-term strategies to attract the most talented individuals to cancer research. We need to create a stable cadre of well-trained technical, biological, behavioral, medical, and public health scientists dedicated to the cancer research enterprise. And, as the interdisciplinary environment increasingly becomes a way of life for researchers, we need to ensure that scientists can and will work together effectively to solve problems.

Our success will depend upon our ability to move beyond traditional educational and research cultures, overcome health financing constraints, and address socioeconomic inequities that have proven to be barriers to progress in the past. The theme for the future is to train scientists to work on problems as integrated, multidisciplinary teams.

To meet these challenges, we must continue to implement training and career development strategies to address a number of crucial issues. We must:

- More adequately prepare basic scientists from all segments of the population and provide them with more attractive career paths. By providing basic scientists in training with the background to conduct research directly related to human cancer and preparing them to collaborate with clinical and population scientists, NCI can provide them with the skills to be successful contributors to cancer research teams. Moreover, increasing trainees'

stipends to levels more reflective of their education and skills will help ensure that careers in basic science will continue to remain attractive.

- Reverse the migration of talented and creative physicians from research to practice. This is the single most threatening consequence to cancer research from the shifting economics of the health care system. We must use more effective means to train clinical investigators and ensure they have protected time to conduct the patient-oriented research that ultimately will translate basic discoveries into better methods for cancer prevention, diagnosis, and treatment. These investigators must receive the necessary intensive training and education that guarantees informed consent and provides maximum safety for patients participating in research.
- Increase the numbers and stabilize the careers of cancer prevention, control, population, behavioral, and public health scientists from all segments of the population. The discoveries of scientists dedicated to prevention, early detection, behavior modification, and risk factor analysis will have a major impact on reducing future cancer incidence and mortality. We must develop better ways to train these scientists to function in interdisciplinary research settings and work effectively with patient-oriented and basic scientists. We also must provide these scientists with protected time in which to conduct research.
- Create a research community that is ethnically and racially diverse. We need scientists who are particularly sensitive to the factors that lead to disproportionate cancer incidence and mortality in underserved populations and who are prepared to conduct research that will help overcome the cultural and socioeconomic barriers responsible for the unequal burden of cancer.
- Attract and integrate technical and informatics experts from all segments of the population into cancer research. Specialists in these disciplines are likely to provide a critical driving force for future progress.

COMMUNITY OUTREACH, INFORMATION DISSEMINATION, PUBLIC HEALTH EDUCATION:

NCI has designated Cancer Communications as an Extraordinary Opportunity for Investment. As is true for many other areas, activities related to communication to minority and underserved populations are intertwined with our efforts to communicate to all about cancer. To maximize the effectiveness of all our communications and to support communications research, planning, implementation, and evaluation, we are taking steps to collect, more effectively analyze, and disseminate critical information about various audience groups.

It is not unusual today for newly diagnosed cancer patients to go to their doctors' appointments armed with printouts from CancerNet or other Web sites and lots of questions. People have more ways than ever to get information: by telephone, fax, email, the World Wide Web, TV, radio, and in person. And the future holds even more choices: automated monitoring of vital signs, voice recognition software, wider use of wireless technology, and other technologic advances to make it easier and faster for people anywhere to get access to the best information about cancer.

NCI's opportunity is to optimize the use of these tools while enhancing the absolutely essential interaction of patients with their doctors and nurses. Indeed, new communication tools can facilitate partnerships between patients and their physicians. We must push forward the frontiers of technology in support of the public, patients, their families, and medical teams to ensure access to individualized, high quality, NCI-validated information. From primary prevention to survivorship and end of life issues, communication empowers people to make informed cancer-related decisions and to engage in behaviors that will improve their health.

To build on our progress in refining health communication theories and interventions, we must close major gaps in our understanding of how people access and use health information as well as the gaps between what is known and what is practiced. We must:

- Provide accurate and balanced information about all areas of cancer prevention, diagnosis, treatment, and care, including complementary and alternative therapies to all.
- Learn how to help all people distinguish important health risks from insignificant ones and make informed choices despite exposure to contradictory or inaccurate health messages.
- Inform physicians, nurses, and other health care providers from all segments of the population of emerging best practices, help them become more effective communicators, and integrate cancer communications into all aspects of cancer care.
- Find and implement the best ways to disseminate research results to the cancer Research community, medical practitioners, patients, at-risk persons, and the public in all segments of the population.
- Increase patient access to and participation in high quality clinical trials to speed the pace of discovery.

- Expand the cadre of health communications scientists and practitioners from all segments of the population who conduct research and apply results.

Through these efforts, we will gain a far richer understanding of how people use health information and access communications technologies of all kinds. We will use that understanding to improve outcomes in cancer prevention, early detection, and treatment, and improve the lives of cancer survivors and those patients receiving palliative care. NCI is committed to reducing, and, ultimately, eliminating cancer-related health disparities, and we are just as convinced that health communications research and health communications activities are critical to meeting this goal.

AREAS OF EMPHASIS

In FY 2001, NCI's National Cancer Advisory Board Ad Hoc Committee on Coding for Research on Minorities established definitive guidelines on how NCI should characterize the Institute's research portfolio regarding ethnic/racial minority research, including the level of detail needed in the financial coding of minority research. In compliance with these guidelines, the objectives listed in Appendix A, though vital to reducing cancer health disparities, are designed to benefit the broader cancer community but are vital to the comprehensiveness of this Strategic Plan. Similarly, Appendices B, C, and D describe ongoing projects that continue to have an impact on the reduction of disparities but are designed to benefit the broader cancer community.

GOAL A: RESEARCH

Objective A.1: Improve capacity and accelerate knowledge through fundamental cancer control and population research.

Action Plan A.1:

Establish Centers for Population Health and Cancer and expand epidemiological investigations to explore racial and ethnic cancer disparities with a focus on cancers for which these disparities are greatest (e.g., breast, cervix, kidney, prostate). Conduct new methodological studies to evaluate factors influencing recruitment and participation of underserved populations in cancer epidemiology studies.

Timeline:

FY 2002 - Concept review, Call for RFA applications;
 FY 2003 - Review applications, award grants, expand epi studies
 FY 2004 - Continue support
 FY 2005 - Continue support
 FY 2006 - Continue support

Estimated Completion Date for Objective: ongoing (evaluate FY 2006)

Performance Measures for A.1:

- Advance understanding of the development and progression of disease.
- Develop new or improved approaches for preventing, or detecting, or diagnosing the onset or progression of disease and disability.
- Develop new or improved approaches for preventing or delaying the onset or progression of disease and disability.
- Develop new or improved approaches to treating disease and disability.
- Advance the understanding of the social and environmental determinants of cancer and the psychosocial, behavioral, and biologic factors that mediate them.
- Develop, apply, and evaluate interventions to improve cancer outcomes and reduce outcome disparities.
- Expand existing epidemiological studies and conduct new studies to evaluate factors influencing participation by specific populations in cancer epidemiological studies
- Disseminate health promotion and disease prevention interventions to the research and provider communities.

Outcome Measures for A.1:

1. Evidence of expanded knowledge of fundamental cancer control through publications, presentations and awards for projects that examine determinants of cancer health disparities.
2. Number of new grants, contracts and intramural projects for fundamental cancer control and population research directed towards minority and underserved populations.
3. Number of new grants, contracts and intramural projects to examine issues related to epidemiological studies with specific populations.
4. Production of targeted evidence-based cancer control interventions included in the Guide to Community Preventive Services.

Objective A:2 Expand cancer control intervention research in prevention, early detection, treatment, and communications.

Action Plan A.2:

- Enhance SPN sites research infrastructure and training in underserved communities. Partner with academic cancer centers to continue developing and testing community based, participatory cancer control interventions addressing disparities. Provide additional funds for pilot cancer control research projects within SPNs.
- Provide supplemental funding to Transdisciplinary Tobacco Use Research

Centers (TURCs) to study differential tobacco use and quitting patterns among underserved populations and support development of more effective interventions to reduce the burdens associated with tobacco use.

- Expand colorectal cancer screening use and follow-up studies. Conduct new intervention research to identify and overcome sociocultural and health care system barriers to the continuing under-use of fecal occult blood testing and flexible sigmoidoscopy, and to address co-morbid illness and other barriers to appropriate clinical follow-up of abnormal findings.
- Expand research on breast and cervical cancer screening for women who have never been screened and those who are not screened regularly. Support new intervention research to identify barriers to screening for women who underuse or never use breast and cervical screening and address sociocultural determinants in planning, implementing, and evaluating these interventions.

Timeline:

FY 2002 - increase support for all actions;
FY 2003 - increase support for all actions;
FY 2004 - provide ongoing support and evaluate
FY 2005 - provide/increase support
FY 2006 - provide/increase support

Estimated Completion Date for Objective: 2006 (expected to be ongoing)

Performance Measures for A.2 :

- Increase number of grants awarded, partnerships developed with academic cancer centers that address barriers to access, and that address sociocultural determinants of cancer outcomes.
- Increase number of supplements provided to Transdisciplinary Tobacco Use Research Centers (TTURCs)
- Increase in number of patients screened for colorectal cancer screening use and follow-up studies.
- Increase support for quality of care assessment with respect to unequal access.
- Establish new and expanded collaborative arrangements with the Centers for Disease Control and Prevention to support new intervention research on barriers to screening for women for cancer disease.

Outcome Measures for A.2:

1. Number of grants awarded, partnerships developed with academic cancer centers that address barriers to access, and that address sociocultural determinants of cancer outcomes.
2. Number of supplements provided to Transdisciplinary Tobacco Use Research Centers (TTURCs).
3. Number of culturally and educationally appropriate cancer awareness campaigns focused on underserved populations.

Objective A:3 Reduce outcome disparities in specific populations by increasing access to state-of-the-art clinical trials in cancer prevention and treatment.

Action Plan A:3

- Expand Clinical Trials Outreach Programs to increase participation by underrepresented populations; establish clinical trials units at minority-serving medical institutions; strengthen clinical trials units at minority-based community oncology sites.
- Increase clinical trials participation by minority physicians and health professionals by implementing an NCI fellowship training program in clinical trials for minority physicians and forums for minority scientists' input into developing clinical trials that address issues of special importance for minority and special populations.
- Expand the radiation oncology-based Cancer Disparities Research Program, initiated in 2002, by funding 3 additional centers. Use this program to expand clinical research infrastructure within communities with disproportionate cancer-related health disparities and examine novel approaches to more closely link these groups with cancer researchers.

Timeline:

FY 2002 -increase support for all actions
FY 2003 -increase support for all actions
FY 2004 - provide ongoing support and evaluate
FY 2005 -provide/increase support
FY 2006 -provide/increase support

Estimated Completion Date for Objective: 2006 (expected to be ongoing)

Performance Measures for A.3:

- Continue support for the Minority-based Community Clinical Oncology Program which addresses the clinical research questions relevant to the disproportionate cancer burden experienced by specific populations.
- Establish collaborations with key minority professional organizations to increase participation of physicians from underserved populations in cancer treatment and prevention trials.
- Increase number of constituent contacts with specific population members made by the NIC's Office of Liaison Activities to ensure that the Institute is aware of and responsive to cancer-related issues affecting specific populations groups.

Outcome Measures for A.3:

1. Increased number of institutions participating in the Minority-based Community Clinical Oncology Program.
2. Increased and sustained number of collaborations with key minority professional organizations.
3. Increased number of minority and underserved patients participating with cancer prevention and treatment trials.
4. Increased number of minority physicians and health care providers participating in cancer prevention and treatment trials.
5. Development of culturally appropriate patient education materials.
6. Development of clinical trials data management infrastructure.

GOAL B: RESEARCH CAPACITY AND INFRASTRUCTURE

Objective B.1: Expand programs to recruit, train, and sustain underserved racial and ethnic minority individuals in cancer research and provide partnership opportunities for training and career development.

Action Plan B.1:

- Expand the Continuing Umbrella of Research Experiences (CURE) Program by: increasing the number of trainee positions on institutional NSRAs by 50; providing new supplemental funding to 10 cancer centers for high school and undergraduate student research experience; funding 10 new minority training positions in Clinical Oncology Career Development Programs; funding 10 new positions for Cancer Education and Career Development Programs in the population sciences; funding 50 new Minority Investigator Supplements to NCI research project grants; funding 20 new mentored career development awards for basic scientists and clinically trained scientists; and funding 10 new Career Transition Awards for basic, clinical, behavioral, and population minority scientists in their first junior faculty positions.
- Promote collaborations between scientists and educators in MSIs and in NCI-designated Cancer Centers through 15 planning grants for developing MSI/Cancer Center research training programs for minorities and outreach education programs for minority communities.
- Increase minority access to training and career development opportunities by improving NCI Internet information services, establishing linkages between public and private agencies that provide related services, and establishing 20 new positions in NCI Cancer Centers that will “broker” the connections between minority individuals seeking research experiences and Cancer Center scientists.
- Integrate the NCI CURE Program and the NCI Minority Institution/Cancer Center Partnership Program more effectively into the Minority Biomedical Support Grant Program in the National Institute of General Medical Sciences.

Timeline:

FY 2002 -increase support for all actions
FY 2003 -increase support for all actions
FY 2004 - provide ongoing support and evaluate
FY 2005 -provide/increase support
FY 2006 -provide/increase support

Estimated Completion Date for Objective: FY 2006 (expected to be ongoing)

Performance Measures for B.1:

- Fund five additional trainees in the NCI Scholars Program and create two new intramural training and career development programs.
- Expand the number of well-trained basic research and in patient-oriented research scientists who are members of specific populations.
- Expand the number of well-trained population, behavioral, and public health scientists in cancer research who are members of specific populations.
- Examine Career advancements made by graduates of the National Research Service Award (NRSA).
- Continue support for the Minority Institution/Cancer Center Partnership (MICCP) Program by funding comprehensive partnerships, planning grants for comprehensive partnerships, and planning grants for more focused collaborative programs.

Outcome Measures for B.1:

1. Number of participants and graduates of the NCI Scholars Program.
2. Number of participants and graduates of the Intramural training and career development program.
3. Number of new individual mentored awards, transition awards for junior independent scientists, and awards to established investigators.
4. Number of participants and graduates of the National Research Service Award (NRSA).
5. Number and projects of the Cancer Prevention Fellowship Program participants.
6. Number of individual and institutional training and career development awards to minority members or scientists focusing on areas of cancer health disparities.
7. Increase in the individual mentored 5-year awards to provide special opportunities for M.D.s in basic or clinical research and for individuals pursuing cancer prevention, control, behavioral, and population science in areas of cancer health disparities.
8. Increased number of Bridging awards that encourage basic scientists and minority scientists to pursue careers in cancer research. These require recipients to undertake mentored and independent research, providing them time to develop independent research programs.
9. Increase number of Transition awards that provide 3 years of protected time following mentored postdoctoral training or for new investigators to initiate successful research programs, especially for minority scientists.

Objective B.2: Strengthen training and education in health disparities research so as to expand minority investigator competition for and minority population involvement in health disparities research.

Action Plan B.2:

- Develop a new track in the Cancer Prevention Fellowship Program to increase the number of scientists studying health disparities. Recruit 2 fellows per year to focus on health disparities research within CRCHD and the Division of Cancer Control and

Population Sciences.

- Expand community-based, cancer control research training within underserved communities. Encourage cancer centers to partner with community organizations and health care institutions in underserved areas to apply for training grant support for community-based clinical and cancer control research training in health disparities research.
- Expand programs to recruit, train, and sustain underserved racial and ethnic minority individuals in disparities research by providing opportunities for these activities in the context of interactions between Minority-Serving Institutions and NCI Cancer Centers.

Timeline:

FY 2002 - Increase funding: Instit.Clinical Oncology Center Development Programs
FY 2003 - Continue funding
FY 2004 - Continue funding
FY 2005 - Continue funding
FY 2006 - Continue funding

Estimated Completion Date for Objective: ongoing programs - evaluate in FY 2006

Performance Measures for B.2:

- Increase the number of participants in the Cancer Centers Program which will bring together diverse scientific disciplines across institutional boundaries.
- Funding of Established Investigator Awards that provide seasoned investigators in the clinical sciences and in cancer prevention, control, behavioral, and population science protected time to conduct research and mentor new scientists.
- Create new Diversified Science Career Development awards to attract technology developers and scientists in disciplines not traditionally associated with cancer research but clearly needed in the future.
- Continue support for the Institutional Education and Career Development Programs, initiated in 2000, to prepare participants for collaborative, multidisciplinary team research settings.

Outcome Measures for B.2:

1. Number of minority scientists supported by the CMBP.
2. Increased number of Established Investigator Awards.
3. Increased number of Diversified Science Career Development Awards.
4. Increased number of Institutional Education and Career Development Programs

Objective B.3: Create partnerships between Minority-Serving Institutions and NCI Cancer Centers.

Action Plan B.3:

- Establish formal affiliations between Cancer Centers and Minority-Serving Institutions (MSIs) in the form of 2 comprehensive partnerships and 1 planning grant for a comprehensive partnership to enhance the research capabilities of MSIs, and improve the effectiveness of Cancer Centers in serving minority communities.
- Provide supplemental funding to existing and new Cancer Centers for health disparities research, to reduce the heaviest cancer burdens among disadvantaged populations, address disparities in risk factors, access to prevention interventions (e.g. smoking cessation, dietary change, physical activity), quality cancer care, and clinical trials.
- Provide supplements to investigators and cancer centers to expand research on disparities in survivorship, including ethnic, cultural, socioeconomic, and institutional factors affecting the quality and length of cancer survivorship in underserved communities and strategies to help cancer patients and their families make the transition to extended and long-term survivorship
- Provide up to 3 years of supplemental funding to cancer centers to stimulate Disparity research, particularly those located in or near underserved communities that experience the heaviest burden of cancer. High priority areas will include disparities in risk factor exposures and access to prevention interventions (e.g., smoking cessation, dietary change, and physical activity), quality cancer care, and clinical trials.

Timeline:

FY 2002 - Increase funding; develop and support partnerships
FY 2003 - Increase funding; support partnerships
FY 2004 - Increase funding; support partnerships
FY 2005 - Increase funding; support partnerships
FY 2006 - Increase funding; support partnerships

Estimated Completion Date for Objective: ongoing

Performance Measures for B.3:

- Number of new and expanded affiliations established between the Cancer Centers and Minority-Serving institutions
- Number of supplementals to support existing Cancer Centers conducting research investigations on health disparities in underserved populations
- Number of supplementals to support investigators and Centers to expand research on health disparities in survivorship in underserved populations.

Outcome Measures for B.3:

1. Number of new grant applications submitted and number funded as the result of programmatic efforts.
2. Number of continuing competing grant applications submitted and funded.
3. Number of investigators and Centers receiving supplemental funds.

GOAL C: PUBLIC INFORMATION, OUTREACH, AND EDUCATION

Objective C.1: Increase access to and use of cancer communications by all populations, especially underserved populations.

Action Plan C.1:

- Analyze and disseminate results of four Digital Divide Pilot Projects to test strategies to increase access to and use of online and other interactive cancer communications by underserved populations.
- Fund additional Digital Divide Pilot Projects and evaluate outcomes.
- Transform the clinical trials Web portal to enable visitors to more quickly find information and resources.
- Build special education/dissemination and diffusion partnership programs to reach underserved communities, test these programs' value in reducing health disparities in underserved communities, and make successful pilot programs available for use by local, regional, and national organizations concerned with cancer and public health.
- Provide one-year competitive supplements to investigator-initiated intervention research grants. Create a supplemental funding mechanism to develop and implement a dissemination and diffusion plan for interventions proven by the original intervention research to be effective in reducing health disparities.
- Fund supplements to NCI research grants for dissemination of evidence-based interventions specifically aimed at reducing health disparities.
- Expand support for advanced training of state health department staff and American Cancer Society volunteers in best practices for using surveillance and intervention evidence data in comprehensive cancer control planning.
- Establish and maintain local and regional partnerships to understand and overcome cancer control infrastructure barriers that contribute to health disparities.
- Establish new comprehensive cancer control program initiative with the Washington, D.C. Department of Health.
- Develop and demonstrate approaches for bringing the latest interventions in cancer screening, care, and treatment, including access to clinical trials, to Native American populations through national and regional Indian health boards, tribal organizations, the Indian Health Service, and established Native American investigators.

Timeline:

FY 2002 - expand support; establish and strengthen partnerships and collaborations
FY 2003 - expand support; establish and strengthen partnerships and collaborations
FY 2004 - continue support; evaluate effectiveness; review funding levels
FY 2005 - continue support; reevaluate level of support
FY 2006 - continue support; strengthen partnerships and collaborations

Estimated Completion Date for Objective : ongoing; Evaluate in FY 2006

Performance Measures for C.1:

- Number of meetings/workshops convened directed to developing survey instruments and new databases to increase access by all populations to cancer information across the digital divide.
- Number of survey and data instruments based on diverse population groups developed and disseminated to program planners and researchers
- Increased support to operate the NCI's database to facilitate planning and evaluation of use of new media and to facilitate communication among researchers and planners.

Outcome Measures for C.1 :

- Number of research projects submitted and funded to develop survey instruments
- Number of hits on the Web site by planners, programmers who interrogate the databases and the categories of information extracted.
- Number of new supplements funded for research on dissemination of evidence-based interventions aimed at reducing health disparities.

Objective C.2: Develop a menu of communication choices to meet the needs of all users, and especially to increase knowledge about, tools for, access to, and use of these choices by diverse populations.

Action Plan C.2:

- Develop new tools and products to facilitate cancer communications for the public, patients and their caregivers, underserved populations, advocacy groups, health professionals, and cancer communicators.
- Continue work with Agency for Healthcare Research and Quality to fund research on decision aids ("Making Quality Count for Consumers and Patients"). Link with Digital Divide Pilot Projects to promote dissemination and use of interactive communication tools, and collect information on current levels of, and barriers to, use.
- Assess the status of low-literacy research and national initiatives in order to develop a strategic plan for low-literacy programs and materials.
- Develop and promote a media toolkit to facilitate the media's use of NCI's resources in preparing cancer-related stories.

Timeline:

FY 2002 - Expand support
FY 2003 - Expand support
FY 2004 - Expand support
FY 2005 - Expand support; begin evaluation process
FY 2006 - Expand support

Estimated Completion Date for Objective: ongoing

Performance Measures for C.2:

- Convene workshops/meetings to assess the needs and type of communications tools needed for populations with low literacy.
- Convene workshops/meetings to develop an interactive system of narratives to convey clearly cancer-related stories and identify methods for effective dissemination

Outcome Measures for C.2:

1. Number of Request for Applications (RFAs) and Program Announcements (PAs) to further characterize approaches to communicate low-literacy research and national initiatives in order to develop a strategic plan for low-literacy programs and materials.
2. Number of communities with demonstrated benefits from the studies as measured by survey instruments and other forms of information gathering techniques.

SUMMARY AND PERSPECTIVES

In this document, an ambitious plan is described that has as its overarching purpose to reduce and eventually eliminate cancer-related health disparities. As the largest of the NIH's institutes, the NCI has a very diverse portfolio of ongoing and anticipated activities in this area. Many of the programs, activities, and individual initiatives that comprise our efforts to reduce disparities in cancer address more than one aspect of the challenge. An attempt has been made to describe these activities in the context of the three-pronged goals of the NIH in this area, namely Research, Research Infrastructure, and Public Information, Outreach, & Education. NCI has ongoing activities in all three areas, and we also will be expanding ongoing activities and creating new activities in all three areas.

Our ultimate hope is that there will come a day when it will no longer be necessary to invest in reducing cancer health disparities because they will be eliminated. Until that day arrives, the NCI will remain committed to the cause.

APENDIX A:

Overarching Objectives that Impact on Issues of the Broader Cancer Community, including the Reduction of Cancer Health Disparities

Research

- Fund additional research based on expansion of prior studies, e.g. the Prostate Cancer Outcomes Study, to examine risk factors associated with late-stage disease - lifestyle, biological and clinical characteristics, and access to care - while accounting for state-of-the-art measures of socioeconomic status.
- Collaborate with DHHS task force to contribute to the training of state health department staff and volunteers from 17 divisions of the American Cancer Society (ACS) in best practices for using data to improve cancer control planning, collaboration with ACS and the Center for Disease Control and Prevention (CDC).
- Continue having the CRCHD address excess cervical cancer mortality throughout the nation through “Think Tanks” and focused interventions.
- Convene of “Think Tanks” by the CRCHD to address the racialization of society and its effect on cancer health disparities.
- Support research on the biologic variability in cancer in terms of tumor aggressiveness, differential response to therapy, genetic polymorphism, and psychoneuroimmunologic factors as mediators of social environment.
- Build on findings from the Prostate Cancer Outcomes Study to examine risk factors associated with late-stage disease - lifestyle, biological and clinical characteristics, and access to care - while accounting for state-of-the-art measures of socioeconomic status.
- Expand systems and methods to enhance the quality of cancer control data on risk, health and behaviors, and screening practices linked to high quality data on cancer outcomes.
- Continue the Current Population Survey (CPS) Tobacco Use Supplements, with the 2003 survey focusing on key tobacco cessation issues, and extend support for analytic tools, resources, and investigator-initiated research to use a decade of CPS Tobacco Use Supplements for evaluating local, regional, and national progress in tobacco control.

- Enhance national and regional data systems to improve measurement of key issues for cancer trends and data on socioeconomic and other demographic measures. Initiate data tracking systems for cancer control and treatment drugs and for over-the-counter prescription drugs and complementary and alternative therapies.
- Support development of a restricted access research data center required for linked databases containing potentially identifiable information.
- In collaboration with the Agency for Healthcare Research and Quality, develop a surveillance and behavioral colorectal cancer screening initiative to improve compliance with screening and monitor performance in primary care practices.
- Explore data systems to monitor the use and side effects of spiral-computed tomography for lung cancer and the role of Pap smears versus Human Papilloma Virus testing for cervical cancer screening.
- Expand the Cancer Research Network as a population laboratory for evaluating progress in cancer control and care within integrated health care delivery systems.
- Collaborate with private and public partners to facilitate transition phase of obtaining cancer stage and care data in 2003 that is not currently part of routine cancer registration.
- Update linked databases for tracking cancer care, such as the linked SEER-Medicare database, and develop new linked databases related to cancer control and treatment at the population level for people under age 65.
- Use statistical and methodological research to improve the accuracy and reliability of cancer- relevant measures -- including self-report and biological diet measures, physical activity, and social and psychological behavioral determinants for use in surveillance and epidemiological research.
- Develop statistical and graphical methods, software applications, and other technologies relevant to geospatial and mapping research.
- Expand systems and methods to enhance capacity for exploring causes of cancer, generating new hypotheses on risk, and identifying new opportunities for cancer control interventions.

- Encourage use of NCI Atlas of Cancer Mortality in the United States, 1950-1994, and other population-based data systems (e.g. Long Island Breast Cancer Study), as a source of study from high-risk areas.
- Provide critical tools for cancer control, especially at the community level, by developing a Web-based Internet lecture series on use of Geographical Information Systems (GIS) and other data sources for cancer control research; working with the National Science Foundation on use of geographical data; and developing analytic and graphic software for visualizing disease patterns and advancing use of disease-exposure GIS applications.
- Support workshops and pilot study on enhancing surveillance systems for research in gene-environment interactions and identifying the potential for cancer control interventions at the population level.
- Increase the number and broaden the geographic distribution of NCI-designated Cancer Centers by awarding new Cancer Centers in geographic areas not presently covered.
- Provide supplemental funding to existing and new Cancer Centers for health disparities research, to reduce the heaviest cancer burdens among disadvantaged populations, address disparities in risk factors, access to prevention interventions (e.g. smoking cessation, dietary change, physical activity), quality cancer care, and clinical trials.

Research Capacity And Infrastructure

Improve cancer registry data by expanding Surveillance, Epidemiology, and End Results (SEER) coverage, improving the quality of all population-based cancer registries, and enhancing SEER as a research resource.

- Support 2 to 5 new SEER registries to improve coverage of key populations: non-Mexican Hispanics, residents of Appalachia and other rural areas (especially those of lower socioeconomic classes), rural African Americans, American Indians, and populations with high cancer mortality rates.
- Enhance national and regional data systems to measure disparities in cancer-related health behaviors and screening practices. Expand support for supplements to national and regional surveys to enhance data on socioeconomic and other demographic factors associated with disparate cancer outcomes.
- Support statistical and methodological studies to improve accuracy and reliability of data on socioeconomic determinants of cancer rates and risk, health behaviors, and screening

in national and regional populations. Expand use of modeling and geographic analyses to examine the unequal burden of cancer.

- Develop new data collection methods for socioeconomic and cultural factors including measures, data sources, and data linkage.
- Examine informed consent provided with prostate cancer screening and treatment in different age, race-ethnicity, and socioeconomic groups as a measure of quality of care in situations where there is uncertainty about the efficacy of interventions.
- Conduct methodological evidence-based research to ensure that survey, epidemiological, and clinical research involving cancer risk factors exhibits cross-cultural equivalence.
- Enhance use of the NCI Cancer Progress Report process to monitor health disparity reductions and reach Healthy People 2010 goals.
- Refine and harmonize federal cancer registry programs (i.e. four new expansion registries added to SEER to improve coverage of key populations) to meet SEER standards for data quality, and use the data for reporting and for cancer control activities.
- Identify registry operations that will help meet SEER standards by implementing and improving quality assurance procedures and use of data quality profiles.
- Improve coordinated federal cancer registry programs through development of enhanced information technology systems for registry operations in SEER programs.
- Support innovative statistical survey research methodology and complex regression models for combining data from diverse sources to meet the needs of the evolving national cancer surveillance data.

Expand systems and methods to enhance the quality of cancer control data on risk, health and behaviors, and screening practices linked to high quality data on cancer outcomes.

- In collaboration with the Agency for Healthcare Research and Quality, develop a surveillance and behavioral colorectal cancer screening initiative to improve compliance with screening and monitor performance in primary care practices.

- Explore data systems to monitor the use and side effects of spiral-computed tomography for lung cancer and the role of Pap smears versus Human Papilloma Virus testing for cervical cancer screening.
- Expand the Cancer Research Network as a population laboratory for evaluating progress in cancer control and care within integrated health care delivery systems.
- Collaborate with private and public partners to facilitate transition phase of obtaining cancer stage and care data in 2003 that is not currently part of routine cancer registration.
- Update linked databases for tracking cancer care, such as the linked SEER-Medicare database, and develop new linked databases related to cancer control and treatment at the population level for people under age 65.
- Use statistical and methodological research to improve the accuracy and reliability of cancer- relevant measures -- including self-report and biological diet measures, physical activity, and social and psychological behavioral determinants for use in surveillance and epidemiological research.
- Develop statistical and graphical methods, software applications, and other technologies relevant to geospatial and mapping research.
- Expand systems and methods to enhance capacity for exploring causes of cancer, generating new hypotheses on risk, and identifying new opportunities for cancer control interventions.
- Encourage use of NCI Atlas of Cancer Mortality in the United States, 1950-1994, and other population-based data systems (e.g. Long Island Breast Cancer Study), as a source of study from high-risk areas.
- Provide critical tools for cancer control, especially at the community level, by developing a Web-based Internet lecture series on use of Geographical Information Systems (GIS) and other data sources for cancer control research; working with the National Science Foundation on use of geographical data; and developing analytic and graphic software for visualizing disease patterns and advancing use of disease-exposure GIS applications.
- Support workshops and pilot study on enhancing surveillance systems for research in gene-environment interactions and identifying the potential for cancer control interventions at the population level.

Increase the number and broaden the geographic distribution of NCI-designated Cancer Centers.

Public Information/Outreach/Education

Improve dissemination of information on cancer trends and progress in cancer control and care to researchers, public health professionals, the public, policymakers, advocates, and legislators.
Enhance training opportunities in surveillance, health services.

- Continue public and private collaboration to expand local and national surveillance data dissemination for research and health policy planning, applying information technology to enhance visual quality, user interaction, and clarity for a diverse audience.
- Continue the NCI Cancer Progress Report as a vehicle for disseminating summaries of cancer progress, including new measures and a 2003 feature on dissemination of cancer treatment advances.
- Support a Surveillance Evidence Review on cancers with adverse trends to evaluate research on epidemiological, surveillance, and treatment factors influencing trends, and collaboratively apply the data to develop focused health policy and plans to improve trends. (Note: the Surveillance Evidence Review on cervical cancer in underserved populations is underway)
- Fund existing surveillance and applied research networks and consortia to conduct intensive training programs, provide sabbatical opportunities for research professionals, and initiate and develop academic curricula on surveillance, health services, and applied research.

Establish new data collection and analysis strategies to support cancer communications planning and evaluation.

- Analyze data from the Health Information National Trends Survey (HINTS) and make results available to researchers and program planners as early as possible.
- Explore the use of Internet-based data collection to follow a subset of people interviewed as part of HINTS.
- Conduct a HINTS survey of cancer survivors in parallel with the HINTS public survey. The HINTS-S, or HINTS survivors survey, will collect data on survivors' use of different media, their risk perceptions, cancer-related behaviors, personal cancer experiences, and

use of complementary and alternative medicine. We will assure adequate representation of diverse population groups.

- Explore the need for national data collection about health professionals' communication practices.
- Continue to operate the NewMediacy listserv and health and lifestyle database to inform NCI's planning and evaluation efforts about which audiences use which new media, and how they use them.
- Create a searchable database of cancer-related communication research reports accessible to researchers and program planners.

Accelerate the pace of research and development of interventions in cancer communications.

- Continue to support Centers of Excellence in Cancer Communications Research.
- Establish interdisciplinary training partnerships and fund health communications laboratories to develop and conduct training programs for researchers in growing areas, including risk communications and interactive health communications.
- Fund dissemination and diffusion supplements to grantees with proven interventions ready for dissemination. These supplements would allow planning and piloting of dissemination with a focus on minority and underserved populations.

APPENDIX B:

Selected Ongoing Research Activities related to the Reduction of Cancer Health Disparities

CRCHD has initiated a series of discussions with the National Human Genome Research Institute (NHGRI) on health disparities and plans to develop collaborative programs on how best to use the tools developed by the Institute to address genetic bases for cancers in different populations and how environmental factors contribute to the development, progression, and outcome of cancers in these populations.

Although cervical cancer mortality rates have diminished for the U.S. population as a whole, some geographic areas still have high death rates from this disease though it is relatively easy to detect and treat. Under the leadership of CRCHD, NCI is reassessing the mortality rates for cervical cancer in different populations using SEER and other national databases to identify geographic regions of greatest mortality for disease. It is expected that with closer examination of these mortality “hot spots” further discoveries about the populations effected and their environment are expected to lead to improved delivery of patient care.

Within CRCHD, NCI’s Special Populations Networks for Cancer Awareness Research and Training (SPN) are networks of 18 institutions that build relationships with community-based programs to foster cancer awareness activities, increase minority enrollment in clinical trials, and develop minority junior biomedical researchers through cancer control, prevention, research, and training programs in minority and underserved communities. In the first year of this program, each SPN has (1) developed new culturally and educationally appropriate cancer awareness campaigns focused on African American, Asian American, Pacific Islander, Latin American, Native American, and low-income Appalachian white populations and (2) built collaborative, community-based infrastructures for cancer control research. Also, many of the SPNs have worked to increase the competitiveness of junior and minority investigator-initiated research applications submitted for peer review by participating in three rounds of the developmental research grants program sponsored by NCI.

NCI is focusing increased attention on how best to translate research into improved outcomes for all populations. NCI leadership helped organize the Department of Health and Human Services (DHHS) task force on the dissemination of health promotion and disease prevention interventions. The Institute has contributed to the training of state health department staff and volunteers from 17 divisions of the American Cancer Society (ACS) in best practices for using data to improve cancer control planning, collaboration with ACS and the Centers for Disease Control and Prevention (CDC). The Institute has worked with the CDC to develop a targeted dissemination plan for evidence-based cancer control interventions to be included in the Guide to Community Preventive Services.

NCI has worked with the Agency for Healthcare Research and Quality and CDC to promote the adoption of best practices for clinical and public health approaches to tobacco control. The Institute is working with the ACS and NCI-funded researchers to disseminate a dietary intervention through faith-based organizations, tested with the NCI 5-A-Day research grant support, and found to be effective in two studies conducted among six African American churches in North Carolina and Georgia. Working with ACS regional and African American church volunteers, NCI is supporting dissemination research of a unified Body and Soul program in nine matched pairs of African American churches in three regions, and ACS will provide sustained support for the intervention.

NCI's SEER cancer registry program has been expanded to cover more of the racial, ethnic, and socioeconomic diversity of the United States, allowing for better description and tracking of trends in health disparities. Methodological studies are seeking better ways to measure socioeconomic factors and determine their relationship to cancer incidence, survival, and mortality. In addition, NCI supports a growing body of research to examine the environmental, sociocultural, behavioral, and genetic causes of cancer in different populations and apply these discoveries through interventions in clinical and community settings. These interventions cover topics such as tobacco control, dietary modification, and adherence to screening practices. Recognizing the broad relevance of this research to other disease outcomes, NCI collaborates with other Federal agencies in supporting important research initiatives, including co-funded research with the Agency for Healthcare Research and Quality (AHRQ) under its initiative, "Understanding and Eliminating Minority Health Disparities."

We have expanded and improved the efficiency and utility of SEER on several fronts. Four new SEER registries have expanded coverage of rural Whites and Blacks, non-Mexican Hispanics, American Indians, and states with high poverty and/or cancer death rates. Collaborative ventures with the Centers for Disease Control and Prevention (CDC) and other registries coordinate collection and use of national and state cancer data. Simpler, standardized rules for data collection create consistency among U.S. population-based cancer registries.

We have expanded data on risk, health behaviors, and screening at the state and local level. We have collected nationwide tobacco tracking data and conducted an in-depth evaluation, through the Cancer Research Network, of tobacco control delivered within medical practices across the United States.

We have enhanced the dietary data collected in the National Nutritional and Health Examination Surveys by the National Center for Health Statistics in order to improve tracking of progress made towards achieving the Healthy People 2010 nutrition objectives relevant to cancer control.

The 2000 National Health Interview Survey Cancer Control Topical Module - a survey of cancer risk, health behaviors, and screening conducted in collaboration with the National Center for

Health Statistics was released in the fall of 2001. This survey provides data for tracking progress in cancer control health practices, genetic testing issues, and other cancer-related health objectives.

We have used survey data to assess how community physicians use new knowledge about cancer risk, screening, and treatment. A completed national Survey of Colorectal Cancer Screening Practices in Health Care among 2,212 physicians helps identify potential targets for improving compliance with recommended screening. A national Physician Survey on Cancer Susceptibility Testing examined comfort with and use of genetic susceptibility testing among 1,250 physicians.

NCI has expanded research on the adoption of new advances in cancer treatment and how their use affects quality of life and patient-centered outcomes. We have evaluated the diffusion into the cancer community of new cancer treatment advances; especially those highlighted by successful clinical trials, the NIH Consensus Development Conference reports, and NCI clinical alerts. For example, patterns of care studies are drawing from a rich abundance of existing SEER registry data to quantify adoption of recommended treatments for breast and colon cancer. These ongoing studies and the Cancer Care Outcomes Research and Surveillance Consortium (CANCORS) are expected to provide the basis to evaluate cancer treatments, quality of care, and their effect on quality of life and other patient-centered outcomes. We have supported projects focused on the economics of cancer and on using claims data for evaluation of cancer health services.

We also have expanded our research among cancer survivors, examining lifestyle and quality of life in relation to cancer treatment and survival. For example a seminal workshop co-sponsored by public and private cancer organizations examined the role of physical activity across the cancer continuum. An NCI-funded study - Health, Eating, Activity, and Lifestyle and Breast Cancer Prognosis - examined these factors among ethnically diverse community-based breast cancer survivors.

We have been linking data on risk, screening, and treatment to outcomes. An NCI/CDC/California State Department of Public Health venture, the California Health Interview Survey, provides a rich assessment of social, cultural, health system, and policy measures critical to local cancer control policy and planning in the diverse population of California. We also have linked mammographic screening data in diverse communities to cancer outcomes in the NCI-supported Breast Cancer Surveillance Consortium in order to provide national measures of mammography performance.

To better track emerging trends in cancer and apply the data to reduce the national cancer burden, we have been providing new tools for exploring patterns and generating hypotheses for etiologic research, which examines the causes behind cancer cases.

- The Geographic Information Systems (GIS) for cancer control is an analytical tool that complements the Atlas of Cancer Mortality in the United States. While the Atlas of Cancer Mortality in the United States shows geographic patterns of cancer death rates and makes it easy to uncover cancer patterns, Geographic Information Systems (GIS) provide tools for exploring patterns and generating hypotheses for etiologic research. Two major improvements have been made to this specialized GIS. The first, the Geographic-Based Research in Cancer Control and Epidemiology, supports use of the Cancer Atlas, GIS and other innovative methodological research in geospatial statistical analysis. Collaboration with the National Science Foundation Digital Government Initiative supports method development for better visualization of spatial data. This effort will help both scientists and non-scientists to comprehend these data.
- Cancer Profiles, a system for identifying geographic areas in greatest need of cancer control activities, is being constructed in collaboration with CDC and other partners. The Web-based interactive design will allow users to identify regions that match user-specified statistical and trend comparison criteria. The system will provide high quality data on ecological measures, such as demographic, socioeconomic, and other such measures that relate the effects of physical and social environments to cancer trends. Ecological measures are valuable for planning cancer control strategies. This system will use advanced statistical methods to pinpoint the cancers that contribute most to recent state and national trends.
- Analytic tool kits developed by NCI, such as SEER Stat and associated statistical modules, facilitate the use of SEER and other cancer surveillance databases. Enhancements include ease of use, innovative new statistical measures, and improvements to existing measures and statistical modules. Development of database management systems for SEER is making registry operations more efficient and promoting uniform standards and consistency of implementation.

In summary, it is NCI's goal to build a stable, racially and ethnically diverse cadre of basic, clinical, behavioral, and population scientists trained to work together effectively and to use the most advanced technologies in building our knowledge base and in translating discoveries into more effective cancer prevention, detection, diagnosis, and treatment strategies.

APPENDIX C:

Selected Ongoing Activities to Build Research Capacity and Infrastructure related to the Reduction of Cancer Health Disparities

Greater participation of minority health professionals in clinical trials is essential to our efforts to explore research questions about cancer-related health disparities. The Minority-based Community Clinical Oncology Programs have for many years sought to address clinical research questions relevant to the disproportionate cancer burden experienced by specific populations. NCI also has established collaborations with key minority professional organizations to increase participation of physicians from underserved populations in cancer treatment and prevention trials.

NCI has launched the Minority Institution/Cancer Center Partnership (MICCP) Program in Fiscal Year 2001 by funding two comprehensive partnerships, two planning grants for comprehensive partnerships, and 12 planning grants dedicated to more focused collaborative projects and programs ranging from research to training. This program reaches out to the five major minority institutions with medical schools, as well as to more than 300 smaller institutions dedicated to educating African Americans, Hispanics, Native Americans, and other groups underrepresented in biomedical research. Research-intensive NCI Cancer Centers, together with culturally sensitive minority-serving institutions (MSIs), offer an entirely new set of opportunities for training more minority scientists, expanding the cancer research capability of MSIs, and focusing more research and community outreach programs of Cancer Centers on minority health disparities. In the next year, the MICCP will seek ways to integrate its efforts with NCI's Special Populations Networks for Cancer Awareness Research and Training and the Minority Biomedical Support Grant Program, sponsored by the National Institute of General Medical Sciences at the NIH.

The Comprehensive Minority Biomedical Program (CMBP) aims to increase the number of minority scientists in biomedical research and enhance the careers of those already in the field. CMBP programs include NCI's newest training initiative for underserved minorities, the Continuing Umbrella of Research Experiences (CURE), and a host of other training opportunities targeting high school students through established researchers. Increasing the representation of ethnic and minority individuals in research and clinical care is crucial to ensure that important research questions about disparities are investigated and that discoveries are translated into community practice.

Through its Cancer Centers Program, NCI has established the foundation for an overarching research framework that will bring diverse scientific disciplines together across institutional boundaries. NCI-designated Cancer Centers continue to evolve as key strategic partners of NCI. In 2001, NCI added a Center in Missouri and will fund a new planning grant for developing a Center in South Carolina. In addition, the number of Cancer Centers with the "Comprehensive" designation increased in 2001 to 38. NCI has also been working with institutions in Missouri,

Georgia, New York, Louisiana, Rhode Island, Florida, West Virginia, Kentucky, Arkansas, Massachusetts, and Michigan to develop Cancer Centers.

NCI is providing training for new scientists focused on health disparities through the Cancer Prevention Fellowship Program and the Special Population Networks for Cancer Awareness Research and Training (SPNs). In the Washington, D.C., area, fellows have research and mentor opportunities through the NCI-funded Latin American Cancer Research Coalition SPN. This arrangement provides participants with field experience at Georgetown University and Washington Hospital Center. Similarly, a Cancer Prevention Fellow is working closely with investigators at the Johns Hopkins Oncology Center in new prevention and control programs targeted to African American men in Baltimore City and Prince George's County.

In the area of training, a variety of individual and institutional training and career development awards are being employed to meet the needs of new and established investigators and NCI's anticipated research priorities. Special programs have focused increased resources on career tracks for M.D.s in cancer research, behavioral and population scientists, minority scientists, and scientists in highly technical fields important to the future of cancer research. Education programs for health practitioners and the public are being more effectively integrated and made accessible through improved national networking and exploitation of informatics technologies. The NCI training activities are varied and include programs aimed at all stages of career development. Included are programs open to all as well as programs specifically tailored to meet the needs of minority scientists.

- Individual National Research Service Awards are aimed at providing a stable cadre of well-trained basic scientists from all segments of the population.
- Individual mentored 5-year awards provide special opportunities for M.D.s in basic or clinical research and for individuals pursuing cancer prevention, control, behavioral, and population science. Interest in these awards has increased dramatically over the last 2 years, resulting in a three-fold increase in the number granted – evidence of both the need for and effectiveness of these programs.
- Bridging awards encourage basic scientists and minority scientists to pursue careers in cancer research. These awards require recipients to undertake mentored and independent research, providing them protected time to develop independent research programs. These special bridging awards have increased steadily since their inception 5 years ago and are on target for achieving their strategic objectives.
- Transition awards provide for 3 years of protected time following mentored postdoctoral training or for new investigators to initiate successful research programs. These awards are now in place for NCI's two most critical areas of need: medically trained doctors in basic and clinical research and population scientists. A new transition award is now

available for minority scientists. Because we have not been able to achieve our targeted objectives for transition awards during their first few years, we are taking new measures to increase their accessibility and attractiveness.

- Established investigator awards provide seasoned investigators in the clinical sciences and in cancer prevention, control, behavioral, and population sciences protected time to conduct research and mentor new scientists. The number of these awards has increased since their introduction, and their availability appears to be helping to curtail the migration of physicians from research to patient care.

New diversified sciences career development awards attract technology developers and scientists in disciplines not traditionally associated with cancer research but clearly needed for the future. Institutional awards are 5-year awards for developing and conducting training and career development programs. These awards achieve special goals by establishing specific requirements and assembling mentors whose skills support program objectives.

- National Research Service Awards, NCI's mainstay for training basic scientists, include special provisions for curriculum and research environments that expose all trainees to cancer-related opportunities and important new research approaches of the future.
- Institutional Clinical Oncology Career Development Programs prepare the next generation of clinical scientists to design and implement hypothesis-based clinical trials and to collaborate with basic scientists. There are now nearly 20 of these programs in place throughout the nation.
- Institutional Education and Career Development Programs, initiated in 2000, prepare participants for collaborative, multidisciplinary team research settings. This program is proving to be extremely successful in meeting NCI's strategic needs by stimulating the initiation of new, forward-looking training programs in prevention and control, imaging sciences, outcomes research, and molecular pathology.
- The Continuing Umbrella of Research Experiences (CURE) Program engages minority high school and undergraduate students and provides them with assistance through all stages of training and career development needed to become independent investigators.
- Minority Institution/Cancer Center Partnerships have the potential to link over 300 Minority-Serving Institutions with NCI Cancer Centers to increase the number of minority students engaged in cancer research; strengthen the research capabilities of minority institutions; and support Centers in reducing cancer incidence and mortality in minority populations. Several comprehensive partnerships are now operating, and numerous planning activities are being supported to enhance more focused collaborations between NCI Cancer Centers and minority-serving institutions.

APPENDIX D: Selected Ongoing Activities to Expand Community Outreach, Information Dissemination, and Public Health Education related to the Reduction of Cancer Health Disparities

NCI's Office of Liaison Activities was established to provide a consistent point of contact with diverse consumer constituencies, to ensure that the Institute is aware of and responsive to cancer-related issues affecting specific population groups.

Two new series of cancer patient education materials for low-literacy populations focus on information in two areas important to these groups, pain management and clinical trials. The pain management information was adapted from materials developed by the Johns Hopkins University Comprehensive Cancer Center. The clinical trials series was created specifically for African American and Native American groups.

NCI collaborated with the Howard University Cancer Center and Meharry Medical College to increase access to and involvement in clinical trials by underrepresented populations, minority researchers, and patients and physicians who have not previously participated in clinical trials research. NCI provided support for the development of culturally appropriate patient education materials and for clinical trials data management infrastructure.

To communicate and promote the use of important information about cancer trends, NCI has been improving dissemination and diffusion of data resources and methods. We have added mechanisms that provide important information about cancer trends not only to cancer centers, universities, and health departments, but also to cancer advocates and the public.

- Special resources have been mounted on the Web to make complex national data systems such as SEER much easier to use. These resources include the Current Population Survey Tobacco Use Supplements, the improved SEER-Medicare Linked Database, the International Dietary Assessment Calibration/Validation Research Register, SEER*Stat, SEER*Prep, SATSCAN, CANSURV, COMPREV, the CanQues, and SEER training Web-hosting services.
- NCI is examining the potential use of workshops to teach proficient use of methodological and statistical applications. Examples include workshops on using analytic methods for complex medical claims data in the SEER-Medicare Linked Database and exploration of innovations in statistical methods for surveillance.
- We are collaborating with public and private partners to organize and streamline data collection, statistical methods, and reporting processes. For example, starting with the Web-based statistical module CanQues, a major international publishing company is

helping to make a “core engine” that can be used online to retrieve cancer statistics. Collaborations with the Breast Cancer Surveillance Consortium and the Breast Imaging Reporting and Data System Committee of the American College of Radiology are releasing the research potential of national mammography screening data by streamlining and standardizing data collection instruments and software systems.

- NCI has published the Cancer Progress Report, in hard copy and on the Web, to detail progress in our Nation’s fight against cancer to all Americans.

NCI scientists have also been studying the impact of interventions on cancer trends at state, local, and national levels through support of the Cancer Intervention and Surveillance Modeling Network (CISNET). CISNET explores the causes of cancer incidence and mortality trends, analyzes whether recommended interventions are working, predicts the impact of new interventions, and studies optimal control strategies. As requested through state health departments and American Cancer Society (ACS) divisions, and in collaboration with CDC and ACS National, we are building relationships between cancer control planners and CISNET to model the impact of disseminating effective interventions on cancer trends.

Planning for the Health Information National Trends Survey (HINTS) of 9,000 participants is well underway. HINTS, to be launched in 2002, will be the only national survey focused on cancer communications. It will gather information on health, sociodemographics, and access to health care; knowledge about cancer; risk perceptions; cancer-related behaviors such as cancer prevention and screening; as well as data on such topics as personal cancer experience, social ties, and self-efficacy. The data will be analyzed and made quickly available to the research community to inform future communications research and program planning for cancer as well as other health issues. Data will also be shared with the advocacy community through briefings and special reports.

NCI staff are tapping a health/lifestyle information database to identify and disseminate data on the information needs of specific audiences, develop appropriate educational messages, and identify the best media, locations, and techniques for communicating cancer information. Moreover, staff has developed and maintains a NewMediacy listserv that is narrowing the knowledge gap between the private and public sectors.

A number of pilot projects and educational materials focus on understanding and bridging the digital divide and promoting the benefits of clinical trials.

- Last year, NCI announced a new initiative and, within the same fiscal year, funded four research and development projects to develop unique approaches for overcoming the cancer “digital divide” [a term referring to existing disparities in access to and utilization of the newer means of communication (e.g., the World Wide Web)] by providing underserved groups with access to computers and the wealth of cancer information now

available through computers. Each project involves public-private partnerships, and one has resulted in a joint effort with the Markle Foundation for continued funding

- Research is underway to improve and assess the communication of risks, benefits, and other essential elements of the informed consent and decision making and processes.
- A Web-based educational program is assisting research teams with issues related to the protection of human participants in research.
- Our new Cancer Clinical Trials Education Series provides clinical trials information to the public, health care professionals, and patient groups.

To accelerate research and development of interventions, NCI has taken several steps to address the need for more focused interdisciplinary studies in cancer communications:

- We solicited applications for grants to create up to five Centers of Excellence in Cancer Communications Research in Fiscal Year 2002. The response was excellent, showing that this initiative meets a real need in the research community. The Centers are expected to accelerate scientific developments in cancer communications, increase the number of investigators from a range of disciplines who focus on the study of cancer communications, and train interdisciplinary investigators to conduct cutting-edge communications research directly relevant to the context of cancer prevention, detection, treatment, control, and survivorship.
- NCI also supported a Community Clinical Oncology Program project based at the University of Rochester to collect data from newly diagnosed cancer patients to learn more about their special communication needs. This information will be used for program planning and to assess the need for additional research.
- NCI World Wide Web sites have been enhanced with an instant messaging service to answer cancer questions submitted online, a natural language search system, the online NCI Publications Locator, and new minimum standards for improved navigability, consistency, and usability.
- Research organizations, medical professionals, and commercial vendors are using NCI-provided tools - a glossary that supports the “define terms on this page” function, for example - to enhance their ability to communicate cancer information on the World Wide Web.

- New resources enhance the effectiveness and reach of cancer communications. An online repository of NCI-cleared core information facilitates responses to inquiries from the media, public, and other sources. A new Communication Technologies Research Center for usability testing, technology evaluation and demonstration, and training provides the tools to design evidence-based cancer information products and services, and a new Emerging Technologies Unit searches out and applies new and evolving technologies to cancer communications.
- Plans are in place to ensure access to cancer information for people with limited English proficiency. These include conducting an assessment of public and private initiatives that target low-literacy issues and developing an NCI strategic approach that links these efforts to the NCI Office for Reducing Cancer-Related Health Disparities.

Several activities illustrate our commitment to improving dissemination of NCI research results. We are working to heighten researchers' understanding about the needs of end users of research products from all segments of the population. We are increasing the usefulness of the products so they will benefit all people. And we have put in place several mechanisms to assist scientists in the dissemination of research findings.

To increase the likelihood that all citizens will benefit from our investment in research, we are strengthening NCI's partnerships with voluntary health organizations, HMOs, and community organizations, and are planning to fund in 2002 six to eight competitive supplements to NCI grantees with effective cancer control interventions ready for dissemination.

We are convening, in collaboration with private organizations and other Federal agencies, an interdisciplinary group to develop recommendations for intervention researchers and encourage new partnerships among researchers, funders, and receptor organizations.

- As one component of a novel partnership with the National Institute on Drug Abuse and the Robert Wood Johnson Foundation (RWJF) for the Transdisciplinary Tobacco Use Research Centers (TTURCs), RWJF has funded efforts to assure that research findings are communicated quickly to relevant health professionals and organizations and all segments of the population. Through RWJF funding, each TTURC hired a communications specialist to facilitate communication with the public, researchers, and the media.
- In partnership with the Agency for Healthcare Research and Quality (AHRQ), we have commissioned an evidence-based review of effective strategies to facilitate dissemination of cancer-related interventions. We will communicate the results through the World Wide Web, print, and other channels to attempt to reach all segments of the population.

- In partnership with the Centers for Medicare and Medicaid Services, we are helping to support a national demonstration to test a new Medicare smoking cessation benefit for older smokers, including dissemination of an evidence-based smoking cessation guide for smokers ages 50 and older and a guide for Spanish-speaking Medicare beneficiaries.
- In partnership with AHRQ, we are conducting syntheses of the research in a number of areas, such as dietary behavior interventions, decision aids, and dissemination.

To raise the visibility and prominence of cancer communications, the NCI in 2000 established the Eleanor Nealon Extraordinary Communicators Lecture and Award Series to pay tribute to outstanding communicators. Awardees speak about their personal and professional experiences and are recognized in a public ceremony on the NIH campus.

New NCI education and communications products serve as essential tools for researchers, patients, and health care providers. Recent products include:

- Report of an evidence review of cancer-related decision aids funded through the Agency for Healthcare Research and Quality
- Understanding Cancer Pain series, developed in collaboration with Johns Hopkins Oncology Center
- A searchable Risk Communication Bibliography
- Efficacy of Interventions To Modify Dietary Behavior Related to Cancer Risk
- 5 A Day for Better Health Program Evaluation Report
- A pamphlet for the general public on environmental cancers, developed in collaboration with the National Institute of Environmental Health Sciences and the National Toxicology Program
- Materials on the Web and in print to inform seniors and people with disabilities about Medicare's new policy to provide coverage for clinical trials, developed through a partnership with the Centers for Medicare and Medicaid Services
- A new cancer survivorship series, developed through a partnership with the National Coalition for Cancer Survivorship
- A booklet on genetic testing to help all people at risk for inherited cancers and those who perceive themselves at risk decide whether to explore genetic counseling and testing for cancer susceptibility
- A booklet to improve the way people think about and make use of data in health decision making.

NCI has begun several activities aimed at eliminating the so-called digital divide. NCI is supporting four research and development projects to overcome the digital divide by testing the efficacy of new communications technologies in cancer prevention and education. These projects involve partnerships among NCI-supported Cancer Centers and Cancer Information

Service (CIS) Centers at universities and community organizations and programs including Head Start, urban and rural community groups, senior centers, and computer suppliers. We will assess the results of the pilot projects and disseminate information about promising interventions.

- The New England regional CIS office and the Yale University Cancer Center are partnering with a Head Start Center, a group concerned with urban policy, and a group that supplies computers to children to develop techniques for teaching Head Start parents how to use computers and access health information on the Web.
- The Memorial Sloan Kettering Cancer Center and the New York State regional CIS office are partnering to increase access to cancer information and the use of technology by residents of an economically depressed area in the community.
- The University of Wisconsin and the North Central and Mid-West CIS offices are collaborating to promote the use of, and training by peer advocates for, a computer-based education program among underserved women diagnosed with breast cancer in a rural area in one state and an urban area in another. The project is helping some 280 African American women in the urban area play a larger role in their own care by providing them with access to online information. They are being trained in the use of laptop computers and are learning to get cancer information and support over the World Wide Web. These patients say it helps them connect with people and information at all hours of the day and night, especially when they are worried or have immediate concerns.
- A collaboration between Louisiana State University and the Mid-South regional office of the CIS is examining the use of a low-literacy cancer information computer program to determine its potential to increase the use of new communication technologies for health information by older adults in a group of senior centers.

NCI is also supporting research in tailored communications. For example, NCI-supported researchers have shown that the combination of tailored print materials and a call from a telephone health advisor can have several positive effects. This was the first study to show that women's perceived risks about breast cancer could be changed, and that the changes were maintained a year later. Women who received the combination of tailored communications also were more knowledgeable about breast cancer and mammography and were significantly more likely to get mammograms.

Another group of NCI-sponsored health communications researchers recently teamed up to prepare articles for a special issue of the *Journal of Family and Community Health*. They reported on their efforts to develop communications for special populations, such as Asians, African Americans and Hispanics, and to individualize cancer information. One team showed that focus groups could be conducted through the Internet and therefore could include people who would not otherwise participate. Another group tested the feasibility of a tailored,

interactive computerized cancer pain program for patients. In pilot research, the majority of patients said the computer programs were easy, enjoyable, and informative tools. The computer programs extend the reach of health professionals and permit better reporting of patients' pain and tailored advice based on the patient's unique pain profile.

NCI will continue efforts to increase knowledge about, tools for, access to, and use of cancer communications by the public, consumers, patients, survivors, and health professionals – with a special focus on diverse populations – to accelerate reductions in the U.S. cancer burden.

NCI Health Disparities Budget
(Dollars in Millions)

Institute / Center	FY 2002			FY 2003		
	Research	Infrastructure	Outreach	Research	Infrastructure	Outreach
NCI	\$198.80	\$164.00	\$29.60	\$222.60	\$183.60	\$33.20